

2017-07-05

The potential for lifelong learning in dementia: a post-humanist exploration

Quinn, Jocey

<http://hdl.handle.net/10026.1/10273>

10.1080/02601370.2017.1345994

International Journal of Lifelong Education

Informa UK Limited

All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Please cite only the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content should be sought from the publisher or author.

This is the author's accepted manuscript. The final published version of this work (the version of record) is published by Routledge, Taylor & Francis in *International Journal of Lifelong Education*, 2017. Available at: <http://dx.doi.org/10.1080/02601370.2017.1345994> . This work is made available online in accordance with the publisher's policies. Please refer to any applicable terms of use of the publisher.

The Potential for Lifelong Learning in Dementia: a Posthumanist Exploration

Keywords: dementia, posthumanism, music, words, lifelong learning post-verbal communication

Jocey Quinn and Claudia Blandon

Abstract

Numbers of people with dementia are projected to grow to 682 million globally by 2050 (Batsch & Mittleman, World Alzheimer's Report, 2012). However, despite this escalation, the widely-promoted positive vision of lifelong learning throughout *all* ages does not extend to people with dementia. Constructions of learning for those with dementia are predominantly limited to the management of symptoms. The focus on retrieval of memory does not seem to allow for the emergence of the learner as a 'new beginner' (Biesta, 2015). This paper focuses on a current study, *Beyond Words*, to challenge dominant assumptions about dementia and learning. Using a posthumanist theoretical framework, this longitudinal qualitative study explores the benefits of community music for those who face problems communicating with words: such as those with dementias, autism, learning difficulties and brain damage. Rather than characterizing them as 'non-verbal' it positions them as 'postverbal' and able to communicate in different ways. Moving away from discussions of 'selfhood', the paper uses a posthumanist approach to explore an agentic assemblage including one person with dementia from the study and also explores how another participant experiences materiality and time. It demonstrates that learning and 'new beginnings' and 'becomings' can and do take place at advanced stages of dementia, challenging the assumption that dementia is a wasteland for learning. It also shows how people with dementia have much to teach researchers about living and learning.

Introduction:

Constructions of Lifelong Learning and Ageing

There are multiple readings of lifelong learning in later life: some optimistic, some deeply pessimistic. Some are glib, some instrumental, some emancipatory. Conjuring up visions of a merry old age, the World Health Organisation identified Education and Learning as key factors in social participation and a positive life as an older person (2002). These elderly pleasure seekers claim education as their right. 'It should not be a surprise that older adults need and want to learn. They want to stay interested and keep enjoying life to the best of their ability' (Boulton-Lewis, 2010,1). Initiatives such as the University of the Third Age¹ testify to the energy and the multiple interests of those with the time and resources to continue learning. However, lifelong learning has been dominantly positioned by policy makers as instrumental self-management, to ensure an eternal readiness for the labour market and this extends to later life. Retirement ages are pushed further back whilst jobs for life are a thing of the past. Instead a neo-liberal discourse pushes the ageing individual to train and retrain to be eligible for work. Many researchers of course resist an ethos of functionalism in ageing. Those such as Tett (2006), for example, have demonstrated the capacity for learning to change and resist oppression in older age, particularly amongst older women. At another level Wolf (2009) argues that it is essential for civilization to educate older people and that in particular this enables them to reflect on their knowledge and experience to make an important contribution to culture.

Much of the literature on ageing and creativity seems to be functional, (see for example Addams-Price, 1998, Flood & Phillips, 2007). It is also informed by the sense of the self as a possession that can be lost or recovered. This fixed self is the opposite of the fluid subjectivity celebrated by posthuman thinkers such as Braidotti (2013). Sabati (2015, 213) argues that:

'Like ageing, creativity is inextricably linked to both selfhood and temporality; while the ageing self is often evoked as one that is retrospective, creativity is associated with the prospective; the process of ageing (taken to be a demise in

physical and mental capacity) is experienced as a loss of self, whereas being creative is popularly associated with finding and celebrating the self. An assumption emerges that seems to suggest the older adult's need for a reconstitution of selfhood either through expression, recollection or production.'

In her analysis of the group experience of older people who have taken part in a writing course, she demonstrates that, contrary to popular belief, they do not use creativity to recapture the past but to focus on 'dwelling in the present.' Her work is very useful and important in challenging notions of individualism and the idea that for older people only the past has meaning. However, there is still functionality here, the writing is seen to give meaning to life and there are prizes and publications associated with it, even though it seems to be the group process participants value most. There is also cultural capital to be gained by even being nominally a 'writer'. It is valorised, easy to identify as learning and to celebrate: the opportunities for cultural capital and creativity in dementia are far fewer.

Dementia as a 'wasteland' for learning

Sabati's participants are articulate and have a mastery of words. Dementia is a stage of life where words are much more problematic. Dementia (the term we will use in this paper) is an umbrella term for a range of diseases including Alzheimer's disease and vascular dementia which are characterised by loss of memory. Another characteristic is that speech becomes more difficult to understand, less frequent and eventually may disappear altogether. For those with dementia the idea of retrospectivity, of identity belonging only in the past, becomes even more marked, with memory recovery a prime aim for those working in this field. Jenkins (2014) critiques the person centred interventions that make up the current landscape of dementia care, arguing instead for a dialogic view of the self that is always in a process of becoming through interactions with others. Person-centred interventions such as Reminiscence Therapy (Woods, et al, 2005) and Validation Therapy (Bleathman and Morton, 1992) seek to either 'recognise, preserve or re-unify the self by enabling the (coherent) construction of the person's

biographical narrative...to revive or repair a hitherto 'broken' self' (Jenkins, 2014, 7). Jenkins, on the other hand, demonstrates how people with dementia in Scotland have rejected the idea that they currently have no agency or selfhood and have formed their own campaigning groups. This facilitates the goal of 'a rich sociointeractive environment through which a plurality of selves may thrive' (2014,7); where interacting with others can enable individuals to create a 'third self' beyond the self of the past or the self of dementia.

As Kontos (2004) discusses, a diagnosis of Alzheimer's disease is habitually met with horror because it has connoted a loss of 'the self' and an entry into what has been termed 'social death'. Her own ethnographic research in a care home for people with Alzheimer's in Canada has led her to claim another form of selfhood for people with dementia: 'They interacted meaningfully with the world through activity and engagement rather than contemplation or reflection... selfhood is embodied' (Kontos, 2004, 831). She provides a rich picture of their embodied lives and the pleasures and reciprocal moments therein, which include dancing, singing, socializing and caring.

It seems that in the analysis of dementia the potential for engagement and indeed development has been recognized and celebrated by researchers such as Jenkins (2014) and Kontos (2004). In the context of lifelong learning there seems to be less progression. When it comes to those experiencing, dementias it is the discourse of lifelong learning as self-management that dominates (see for example Mountain and Craig, 2012). Asked specifically to speak about dementia and lifelong learning the Head of Research of the Alzheimer's Society in the UK had this to say about 'the learning that may happen after people have received their diagnosis:'

'it is helpful to people in early stages of dementia to receive training in how to manage their disease, to be provided with strategies to overcome their difficulties, to be assisted in developing their own systems that can support them in managing their symptoms.' (Sorensen, 2012)

Whilst this is admirable, what she deems 'appropriate learning' is couched as containment not expansion, with little sense of the openness to and from something new that constitutes learning rather than training. Research such as that conducted by Cheng, Chow, Song, Yu, Chan, Lee & Lam, (2014) demonstrates that some form of activity is essential for those with dementia living in care homes, but this is posited as holding on to activities they used to enjoy rather than branching out in new ways. This positions that person as outside of the realm of learning, cut off from one of the vital agencies of life. Biesta argues, 'education is not just about the reproduction of what we already know or of what already exists, but is genuinely interested in the ways in which new beginnings and new beginners can come into the world' (2015, 5). Similarly, Guattari sees art as a process of becoming (1984). Dementia is positioned simply as degeneration and outside of the possibility of such generative states.

In this paper we seek to reclaim these notions of beginning and becoming for those with dementia. We will look closely at data from a current study that involves the learning of older people with dementia, amongst others. The study, *Beyond Words*, funded by Arts Council England Research Grants Programme, uses multiple methods to explore how people who face problems using words, such as those with dementia, strokes, brain injury, autism and learning difficulties are included in community music making and the consequences for them and their 'networks of intimacy' (Heath, Fuller & Paton, 2008, 220). Rather than focusing on forms of 'selfhood' as in Jenkins (2014) and Kontos (2004), we will use posthuman theory to examine closely an agentic assemblage which includes one person from our study, Robert and will also examine how another, Jane, experiences time and materiality. We will demonstrate how such theory allows us to recognise different forms of learning during dementia that are neither glib nor instrumental, not necessarily emancipatory nor epoch making, but still material and important. We will conclude by discussing what Robert and Jane have taught us and the implications for ageing research more generally.

Background

Arts and the unspoken

Selfhood and even the category of human has been dominantly linked to words.

Rancière, who is currently fashionable and influential in educational thinking defines the human as one who possesses the ability to 'articulate language' (Rancière, 2010) and democracy as being open to all 'speaking' subjects. This positions those who struggle to use words on the margins, even when it comes to participation in the arts. The idea of 'voice' is a dominant one in educational research, particularly in adult education.

Finding and freeing the voice of the learner is seen as an important pedagogical aim and also saturates popular media of all kinds. Moreover, the notion of 'voice' is tied to a belief in an essential self who 'knows who she is, says what she means and means what she says' (McClure, 2009, 104) and is a fundamental tenet of humanism. By focusing on the unspoken, and taking a posthumanist position that argues against any notion of individualistic selfhood that can be unproblematically released, this paper tries to occupy new epistemological ground.

There is a small amount of literature on the unspoken and music practice, with the most commonly researched areas being autism and dementia Sherratt et al 2004, Sakamoto et al 2013). The emphasis in the literature is on music therapy not on music for social inclusion. The two are very different with community music organisations using music to open up and create inclusive communities rather than directly intervening in the mental health of individuals in a therapeutic way. We have not found any examples in the social sciences where a wide range of different forms of non-verbal conditions are brought together; most studies work with very small groups.

Additionally, unspoken/non-verbal aspects of arts practice like body language, spatial and visual environments, culture and ethos appear to be important aspects of inclusive music practice with wide applicability in all contexts across the arts sector, yet they are not widely researched nor understood. There is some research that connects non-verbal elements across music/dance (Karkow, 2007, 12) and some that looks at non-verbal aspects of music leader's practice (Silverman, 2008). However, only Lee and McFerran (2012) acknowledge that the music leaders' non-verbal work contributes to social inclusion/wellbeing. We have not found any examples of longitudinal qualitative studies of the non-verbal in music practice. Existing theoretical approaches to the non-

verbal in inclusive music practice are inadequate, based on deficit models which see silence simply as a problem to be overcome. Thus the issue poses a significant theoretical challenge, with opportunities for significant innovation.

Literature in the other arts addressing working with people who don't use words has been scarce so far. One example is Vorhaus (2015) who conducted research on a theatre and humour intervention with people with profound disabilities, many of whom did not speak. Vorhaus' research showed that interventions that offer interactive, multisensory experiences to people with profound disabilities 'might draw out and enliven a previously inert and apparently 'unreachable' child' (2015, 178). The Storybox project (Harries, 2013) uses theatre and drama with people with dementia but does not focus specifically on those who do not speak.

Ironically, fiction, is sometimes the most productive creative space for thinking beyond words. For example the recent collection of stories *Pond*, with its minute attention to the materiality of everyday life is a fertile source for thinking through posthuman ideas.

'English, strictly speaking, is not my first language by the way. I haven't discovered what my first language is...I don't think my first language can be written down at all. I'm not sure it can be made external you see. I think it has to stay where it is; simmering in the elastic gloom betwixt my flickering organs.'
(from *Pond* by Claire Louise Bennett, 2015, 45)

There is a bodily language that cannot necessarily be understood in spoken or written terms and this is the realm of communication we explored in our study.

Methodological issues in researching arts practice

The project focuses on community music practice that deliberately engages with those who are socially excluded. Debates on inclusion and socially engaged practice (Bishop 2012) and dialogic art (Kester 2004) have shed light on the important methodological issues that might be faced when designing arts interventions with those who face problems communicating with words. One side of the debate emphasizes the process

in participatory arts practice (Bishop, 2006,), whereas the other side emphasizes the importance of the end product (Kester, 2004). Artists interested in the process of making participatory arts share the notion that inclusion is central to their practice, and consequently are called to use sociological models of analysis, where the process is part of the method (Bishop, 2012). On the other hand, artists interested on the final product of collaborative art face questions on how to measure the final artistic product, and thus called to use models of relational aesthetics (Kester, 2004). The community music discussed in this paper falls under the category of participatory art and is not primarily concerned with the quality of the music produced, but in what positive (or negative) consequences are generated by the process of music-making. This position not only affects the theoretical stance when researching such projects but the methodological one needing time to trace and understand the subtleties of the process. 'Participatory art ...tends to value what is invisible: a group dynamic, a social situation, a change of energy, a raised consciousness'; therefore highlighting the importance of longitudinal studies...it is not only a social activity but also a symbolic one, both embedded in the world and at one remove from it, the positivist social sciences are ultimately less useful' (Bishop, 2012, 7). To understand and convey this material and symbolic process we have adopted a posthumanist approach to our project, not a system of measurement of quantifiable impacts.

Kester (2004) highlights some ethical dilemmas faced by artists who seek to empower disenfranchised communities. Kester warns of 'relationships between artist and participants that are characterised by a degree of paternalism, where the artist remains in a position of relative mastery, operating as a living paradigm of the expressive personality that his or her collaborators can aspire to or temporarily adopt as their own. Active listening and intersubjective vulnerability play a more central role in empowerment projects, as the artist does not always occupy a position of pedagogical or creative mastery' 2004, 151). Both the idea of process and of intersubjective vulnerability are important ones for our project. The music leaders we are observing are not positioned as masters or teachers but as facilitators and we as researchers are also positioned as collaborators in a mutual construction of understandings.

The research study

The study we draw on in this paper is the *Beyond Words* project (2015-2017), which was funded by Arts Council England as part of its first research grants programme. The aim of this programme was to bring together arts organisations and university researchers who already had established relationships to explore the potential social benefits of arts work. It involved researchers from Plymouth University and Plymouth Music Zone (PMZ), a local community music organization. PMZ works with vulnerable adults and children using highly skilled music leaders who deliver a diverse range of innovative and tailored creative music-making activities. PMZ's work aims to empower individuals, families and communities through music. The *Beyond Words* Project worked in conjunction with music leaders already employed by PMZ.

It built on earlier work with older people in care homes and families escaping domestic violence (Quinn and Blandon, 2014a, 2014b) to explore the following research questions:

How do we include and make music with those whose communication is non-verbal?

What benefits do they and networks around them gain in terms of wellbeing/social inclusion?;

What role does the 'unspoken' play in inclusive music leadership overall?;

What are the implications of addressing the 'unspoken' for inclusive practice across the arts sector, how can this help practitioners in fields of Health/Education?;

How does post-human theory, (which is interested in breaking down the dominance of the 'ideal human' as someone who expresses themselves through speech) help illuminate this process: what does this study add to the field of post-human theory?

In this paper we will focus particularly on the first and last of these questions and consider them in the light of those with dementia.

Methods

The research (Quinn, Blandon and Batson, 2017) was a mixed method longitudinal qualitative study of 25 people who either have dementia, brain injury, autism or learning difficulties or are survivors of strokes. The research explored their experience over 16 months of music sessions which are held in residential care homes, centres for learning difficulties and the local organisation centre. The methods included ethnographic observations, which aimed to trace subtle consequences of the involvement over time and interviews with participants' networks of intimacy (family members and support care workers), which considered the lives of the participant and the perceived benefits of the sessions to their networks. Focus groups were conducted with music leaders (and volunteers) to learn how they understand and approach working with the unspoken; and finally visual methodologies (arts workshops for participants), were developed which take as a premise that their responses to the music sessions must be included through non-verbal means.

Ethical issues, including ensuring that participants understand what they are giving to consent to, have been important considerations for the project. This has involved, for example, redesigning consent forms with visual rather than verbal information so that people with learning difficulties can understand them. For participants with dementia it has been necessary to contact and consult with those who have power of attorney. Researchers spent time explaining in person the purpose of the project and how it might help those working in this field in the future to improve services to those who do not speak. In addition to obtaining consent, participants' assent was also taken into account during fieldwork iteratively based on on-going feedback. The vulnerability of all taking part, including family networks and the researchers themselves has been carefully addressed throughout. All the participants have been anonymized but consent has been given to use film of them in academic and research related contexts, but not in publicity materials.

Participant observations, and some filming, have taken place weekly since July 2015 during the delivery of music sessions in different venues. Observation prompts have been developed which look holistically at each session but also provide a posthuman and musical frame. They were developed iteratively with the ongoing fieldwork. They

seek to address the following: bodies; communication beyond words; silence; interaction with things; space; time; group interaction; respect; responsiveness; forms of music making such as rhythm, timbre and pace; inclusion and becoming (of both researcher and participants). In addition discussion between the researcher and the music leaders take place after each session.

Forty four in-depth individual interviews with members of networks of intimacy took place. The purpose of this was to explore the participants' lives with those who know them well and to understand from their perspectives what the music sessions are doing and whether this has any benefits to the networks who support each individual. This recognizes that each participant exists as part of a network or assemblage and is not simply an agentic individual.

Finally, as verbal interviews were not helpful for our participants, arts workshops were designed to allow participants to express their thoughts about the music sessions. The workshops were designed and delivered in conjunction with music leaders and support care workers; in some instances family members also took part in the workshops. The mode of expression varied from large paintings on the floor, communal drawings and working with clay. The workshops were led by a practicing visual artist who is experienced in working in community settings. Music is used as a prompt and to tie the sessions to the partner organization this was provided live by a music leader.

The research team kept research diaries reflecting on meanings and issues thrown up through the research. For example:

I love silence and am always conscious of absence as bitter-sweet. Is this part of what we are exploring when we research what replaces words? (research diary)

What is the meaning of a smile in an otherwise stoic silent face? Does a smile mean assent? Does it mean happiness? Does it mean agency? Or is it simply an involuntary contortion of facial muscles? (research diary)

The project has generated large amounts of what Gale (2016, 2014) calls 'data events', a posthuman move away from a conception of data as something fixed and

authoritative. We found it useful to focus on each participant as part of an assemblage and to analyse all the different forms of information we have concerning them. We started this process with a group analysis involving the two educational researchers, the head of music training from the partner organization and the project artist, bringing multi-disciplinary perspectives into play. The educational researchers then moved to a further close analysis using posthuman theory. In this paper we have chosen to focus on Robert who is 89 and has dementia and on Jane who is 63, and also has dementia. They both live in the same care home. Our aim is to explore whether they can tell us anything new and important about dementia and learning.

Using a Posthumanist Approach

Posthumanism provides the theoretical and methodological frame for the study and for this paper. Existing approaches to the non-verbal in inclusive music practice seem to be inadequate, based on deficit models which see silence simply as a problem to be overcome and the person who faces problems communicating with words as someone who has not attained those elements that are considered essential to being a high-functioning human, namely articulacy and agency. Thus the issue poses a significant theoretical challenge, with opportunities for significant innovation. Rather than focusing on the inviolate individual who possesses a 'self' that s/he can communicate through words, post-human theory moves away from the articulate human to focus on acts and bodies (Braidotti, 2013), on materiality (Barad, 2010) and the agency of things (Bennett, 2010). It validates and explores the significance of silence (Mazzei, 2016) and focuses closely on space and the visual in its methodology (Taylor and Hughes, 2016). As such it provides the ideal approach to this issue. Taking this approach can validate the participants and recognise other forms of living and learning that are not about speech but are equally important.

Posthuman theory moves away from 'mental, discursive and spiritual values that have placed man as the measure of all things', from an ideal of bodily perfection, and from seeing difference as 'pejoration' (Braidotti, 2013, 15). According to Braidotti, humanism has a restricted notion of what counts as human', it reduces the others, "the different", to

a less than human status of 'disposable bodies' 2013, 15). Thus the person who struggles to speak is the ultimate 'disposable body' as s/he seems to have no place in the world of words.

Taylor & Hughes (2016, 5) propose using posthuman research practices in education to critique 'fundamental assumptions underpinning dominant ways of doing education research'.. By questioning humanist binaries (body/mind, theory/practice, self/other, emotion/reason, human/nature, human/animal), posthuman theory seeks to challenge old 'certitudes regarding identity and subjectivity, binaries and boundaries, language and representation, methodology and methods' (Taylor and Hughes, 2016, 7). Posthuman practices 'call for new ways of finding out; to this end, posthumanist researchers lean towards data collection techniques that include arts-based, visual, sensory, movement, sonic and creative writing practices' (Taylor and Hughes, 2016, 19). Despite the above, there are comparatively few longitudinal empirical studies using posthuman approaches, with the exception, for example, of Ivinson and Renold, (2015). In terms of this study, the theoretical works of Braidotti, Barad and Bennett are particularly important and to some extent the ideas of Mazzei are applicable.

Bennett focuses on what she terms 'vibrant matter'. Her argument is that both humans and non-human animals and matter all share the same vibrant materiality and are teeming with life (Bennett, 2010, 5). Moreover such matter cannot be understood in isolation but as part of what she calls an 'agentic assemblage'.

Assemblages are ad hoc groupings of diverse elements, of vibrant materials of all sorts. Assemblages are living, throbbing confederations that are able to function despite the persistent presence of energies that confound them from within...Assemblages are not governed by one central head.. Each member and proto-member of the assemblage has a certain vital force.. but there is also... an agency of the assemblage (Bennett, 2010, 23–24).

Thus instead of the isolated individual who speaks, the focus of meaning is on an assemblage which may include the human but within which the human may not be the

most important element. Instead of positioning some matter as active and some as inert, it is more realistic to see and respect them all as having forms of agency. It is useful to see the condition of dementia through this lens. People with dementia are often positioned, and even in the worst cases, treated, as inert lumps of matter. They are moved into a space of detritus or waste. In several instances during project interviews family members described, with grief, how children or siblings refused to acknowledge or visit their family member because they were no longer a person they could recognize, or indeed an entity worthy of continuing support. In some instances they were openly named as “dead”. Bennett’s work shows how even material considered waste is ‘vibratory’ (2010, 5), teeming with life and this is salutary in respect of people with dementia. Another important aspect of her work is what she calls ‘thing power’. ‘Things too, are vital players in the world’ (2010, 4). This too is helpful in unpicking the power of songs and instruments and recognizing the significance of the objects which surround the person with dementia and trouble or delight them.

Barad (2007) is a posthumanist thinker who has proven very influential. One of her key concepts, drawing on quantum physics, is intra-activity. This places the focus of attention not on the human but on the phenomena generated when different forms of matter are brought together: for example a human and a musical instrument. “Matter is agentive and intra-active-generative not merely in the sense of bringing new things into the world but in the sense of bringing forth new worlds” (Barad, 2007, 170). This is very useful when the focus is not on words but on moments of communication, sparks of new life. This notion of ‘new worlds’ echoes with Biesta’s ‘new beginnings’ and Guattari’s ‘becomings’ (1984) as a chorus of possibilities that we will follow in this paper.

Finally Mazzei follows on from other feminist writers such as Lewis (1993) in considering the function and nature of voice and silence in research contexts (see for example Mazzei 2007, 2016). Thus she draws attention to the silences that always occur in research interviews or the silences participants choose. She challenges the primacy of words as a mode of communication and with them the notion that they tell us something essential and uniquely personal about the person who speaks them.

Moreover voice does not belong to the individual but is distributed across the assemblage.

‘Because “voice” cannot be thought as existing separately from the milieu in which it exists, it cannot be thought as emanating “from” an individual person. There is no separate, individual person to which a single voice can be linked—all are entangled. In Deleuze–Guattarian ontology, there is no present, conscious, coherent individual who speaks the truth of her present or her past ’
(Mazzei, 2016, 158).

Potentially this is helpful for our study as we need not search for the individual voice or lament its lack, but can trace how the participants speak without words in their entanglements with other matter in the assemblage. Nevertheless, despite her interest in voice, Mazzei does not address those who cannot speak or who struggle to communicate with words. We have not found many studies, including posthuman ones, that do so and in this paper we are treading new ground. Those who do not speak are commonly called ‘non-verbal’, but this automatically positions them as deficit, as lacking. Taking a posthuman position where ‘post’ is conceptualized as ‘going beyond’, we have adopted the term ‘postverbal’ for our participants. This helps to capture the sense that there are other ways of being and communicating that move past words. We will now proceed to use this posthumanist approach to explore our research with a participant who has dementia.

Researching with Robert: A new beginner and new beginnings

Robert is 89 and resident in a care home and until recently his wife, who also had dementia, lived there too. Such care homes in the UK are normally privately run and offer residential accommodation and, as appropriate, nursing care to older people. First impressions of Robert are deeply troubling, as he seems to exist in what his stepdaughter Ann calls “a hard place”. He shouts loudly and aggressively and appears to hallucinate whilst struggling to get out of his wheelchair. His presence in the group music sessions was so disturbing that music leaders decided to give him individual sessions in his room.

In her research role the research assistant has spent time week on week for 16months observing our participants as part of the ethnographic study. She observes the music sessions and she keeps detailed field notes. Her introduction to Robert emphasises his vocal presence and the sense that he carries with him something that he is trying to catch hold of, ever out of reach. There is a sense of the uncanny: that Robert is in touch with something that is beyond the limited vision of those around him or on the periphery of sight. By moving away from the verbal (and the rational) he opens up the field of vision. "There is no place that is not haunted by many different spirits hidden there in silence, spirits one can 'invoke' or not (de Certeau, 1984, 108)

Robert makes loud sounds and screams and could be disruptive in the sessions... it looks as though he is hallucinating, trying to reach something/or someone, just beyond him. I was told by the home manager that he sings/makes loud noises all day long in his room listening to the radio, and I can surely hear him from the lobby every time... He often extends his hands in front of him, as if he were trying to reach something, to pick up something. He always looks down trying to collect that 'thing' beyond his reach. I see that in other residents too.

(From field notes)

Although Robert's room contains photographs and books it was only when we conducted an in-depth interview with his stepdaughter Ann that Robert's lifelong love of learning came into view:

'Throughout his life Robert has taken up interests off his own bat. He was a keen racing cyclist, he loved fast cars and motorbikes He enjoyed learning things and doing things...He is a remarkable person'

How did he manage to learn by himself?

He used to buy books. He did buy a teach yourself Russian once, I don't know why!... To my memory he didn't ever go to classes'

(Interview Ann, Robert's stepdaughter)

Robert's stepdaughter Ann is very attached to him and visits the care home regularly spending time with him and talking to him even though there seems to be little response or communication. She took up an invitation to join the music session in Robert's room, a session which was also filmed for the research. Here two music leaders, one female, one male, took in a guitar, sang songs and encouraged Robert to interact with the musical instruments, particularly a tablet. In her interview she described very powerfully what she witnessed when Robert engaged in his individual music session:

'He was very, very calm when they were there. There was an engagement at quite a deep level... I was amazed- they have a laptop which allows you to play musical instruments. One of the things Robert took up and tried himself was the guitar, he didn't have lessons...It was this moving his hand across the laptop to make a sound there was almost a fleeting 'Isn't that wonderful' on the face...That is brilliant you are doing something creative in a way you can't be creative anymore.'

'How did you feel when you saw this?'

To be quite honest I was almost in tears, I feel tearful now,... What I was seeing was the Robert I remembered. The person is still there

Her sense of joy on seeing this was then spread outwards as she returned home and immediately contacted all of Robert's family network.

'I think it is a great comfort to us , it has meant a lot that what I saw is that the real Robert is still there It was very, very comforting to me to know that Robert isn't always in that hard place'

The same session was also filmed. Initial observation by the researchers was:

Watching the film Robert's hands are clasped and no longer reaching. The fleeting moment of creativity seems to captivate everyone in the room. The musicians laugh gently with delight and there is a sense of benediction that seems to extend to everyone there. The people the instruments, Robert's face and body, the room with its flowers

and photographs, the memories of the past forms an assemblage and every aspect has meaning. There are some words but they are not at the centre of meaning.

(research diary)

Studying the film as a group added other dimensions. We explored not Robert as an isolated individual who can only be understood in words, but the agentic assemblage of Robert's body, the room, the flowers, the books, the tablet, the music, the music leaders, the voice of Ann, the filmmaker, the researchers. Robert was not mute and inert but thrumming with life of the past and the life of the now. We focused more closely on the music itself. The 3:4 rhythm of the music was lilting and rocking, creating the maternal sense of a lullaby. Robert weaved in and out of the melody and matched the pitch of the notes played on the tablet. He was not a passive recipient of the music but a creator of harmony. The 'thing power' of the guitar and the tablet had powerful impacts upon him. The songs sang, 'My Bonnie' and 'The Skye Boat Song' were traditional songs of reaching out across the sea to something lost. We saw how Robert was simultaneously a little boy and a very old man. Discussing whether the moment when his face expressed 'How Wonderful' could be called learning, we agreed that it was and it did not need to be repeated to be considered so. The project had shown us that time takes on a new dimension in dementia and that a lifetime of meaning can be compressed into a very short space of time. For Robert a moment was enough. Indeed Ann's interview showed how Robert had pursued new learning throughout his life and then put it down, he was never outcome-oriented and he never sought formal teaching or accreditation. So his moment of wonder was one of a lifetime of new beginnings and becomings. The ripple effect of that moment was also apparent. Ann wanted to share her joy in it with her family across the UK and the USA. She even encouraged her uncle living in the USA to introduce music sessions like these into care homes there.

Was Robert learning? This was the question that engaged us and that we subsequently discussed with other adult educators at the European Network for research into the Education of Older Adults conference in Wroclaw, 2016 . Although there may always be scepticism amongst some, there was also broad recognition of the validity of this claim. Previously Robert did not know that a tablet existed or could make music. At that

moment he did and he engaged with it. Doing so gave him pleasure which he communicated to others. The learning process, which Biesta (2015, 5) defines as a 'new beginning', had been ignited.

However, our existing educational vocabulary is stretched and challenged by Robert's experience. In discussing this process we need to abandon our accepted language and preoccupations as Robert will never be able to explain this experience to us and neither can it be explained away in any well-formulated way. We need instead to look at what Robert is doing not just as learning but also as a form of material poetry formulated through the body (see Quinn, 2015). The eye, the light, the expression, the delight, tells its own story. In Barad's (2007) terms neither Robert nor the music are the matter under question, rather the moment of intra-activity, what happens when the two come together is the real object of enquiry. The message of the spark is that something vital is happening that moment and that moment cannot be erased. This has nothing to do with managing dementia but everything to do with living and learning.

'Is he communicating now with his body rather than speaking?

'I think so'

(Interview with Ann)

Researching with Jane: the researcher as new learner

Turning to Jane, she is the youngest person with dementia in our study. She is only in her sixties with a young but anguished face. She constantly paces around the home and she does not speak:

Jane seems confused, lost..., sometimes she makes gestures as though she is going to start to cry. I can see that she is breathing rapidly as though she has realised something terrible has happened.

(From fieldnotes)

In her silence and sorrow she has a strange dignity. She does not seem to be present at all and indeed all her children have decided that she is "dead", leaving only her husband to visit her. It was very difficult for her to stay seated during the group music sessions and it did not seem hopeful that the planned arts workshop would manage to get her attention.

Nevertheless the artist designed a session where musicians played softly at the periphery whilst Jane was encouraged to play with chalk and with different textured materials. The artist had found that music and arts materials had linked textural qualities which she felt would be useful to exploit. The session was filmed and as researchers we found watching it deeply sad and troubling. Jane's face as the musicians sang "I wish I was Homeward Bound" produced an indelible picture of loss, made worse by our knowledge that in the early stages of her disease she constantly roamed the village where she lived, searching for 'home'. It was hard to put the feelings into words but our bodies responded with tears at the time and feelings of distress and troubled dreams through the following days. As posthuman researchers we 'know' that the body tells us something important but here we felt it and lived it. We were feeling *with* Jane, more than thinking about her.

For much of the session Jane did not seem to connect with what was happening, but finally she turned and looked with some recognition at the musicians. She fingered a sparkly scarf with interest and when she was taken away by a carer she put the scarf around her neck and wore it walking away. For Jane to pay this much attention was remarkable and it taught us something about materiality. Words were gone but matter still mattered. The thrust of Karen Barad's work is to argue that matter makes things happen and here we saw this in action.

Our other learning experience relates to time and meaning. This was a brief moment in time, easy to ignore and see as trivial. Humanist education is linear, working always towards the future and a perfecting of knowledge and the person. However, our experience of time is not really like that, it spirals, moving backwards and forwards. Moments can seem to last forever, years can speed by in an instant. As Deleuze and Guattari say, art can crystallise that sensation: "Even if the material only lasts for a few seconds it will give sensation the power to exist and be preserved in itself in the eternity that exists for that short duration" (Deleuze and Guattari, 1986, 166). A moment such as Jane experienced can hold intense meaning. Jane's husband put this perfectly in his interview when he stressed the value of music interventions:

"Why give up? You shouldn't give up. ...how you quantify the benefit that they derive from these visits is just impossible, apart from that moment in time when perhaps they may just react, that is excellent and then an hour later or minutes later they won't remember that someone was there and they reacted to it, but in the moment, that bubble, why not stimulate that bubble?"

The 'bubble' matters, it is not empty and meaningless, and neither is Jane. They both deserve our complete attention. So the claim is not that Jane is learning something new, but rather that she is teaching us some important lessons about what we need to attend to and how.

Conclusion: Implications for lifelong learning

As has often been argued (see, for example, Freire, 1972, hooks, 1994) learners are the true teachers. Robert, Jane and the other participants in the study teach the lessons that: bodies can occupy time and space differently, that words are not a necessary part of a claim to humanity and they need not be articulated in a learning exchange. It is extremely difficult to shake off humanism as this is what shaped Western thought culturally, socially and through formal education. Moreover, the term posthumanist might tend to suggest that the problems faced by humans are over and solved; which is so far from being the case. Nevertheless humanism has been at the root of many of these problems and in its belief that the human is the arbiter of all things has placed the more-than human world in mortal danger. Posthumanism offers a way of redefining and opening up the category human to include and validate Robert, Jane and others like them in advanced dementia, who are often seen as waste. As Jones and Hoskins (2016) demonstrate in their analysis of a Maori tattoo as a holder of meaning, the primacy of words has not always held in all cultures. There is much to learn from others to free European thinking about what constitutes learning.

In order to recognise that learning takes place in dementia, a new conception of time needs to be employed. Humanism has much invested in the notion of linear time leading to enlightenment. Education grounds its practice in the accumulation of learning over time, leading to the perfected educated person. Posthumanism sees past, present and future as always entangled and always alive and the person as always in a state of becoming. People with advanced dementia have run out of linear time, but they still live in the time of the now (as we all do) and in this time they can learn. These moments of learning time spin and vibrate in ways that are difficult to name but easy to feel. 'We say 'now! 'now! now!' or we count 'more! more! more!' as we feel it bud' (William James quoted in Burdick, 2016,70). For those that love our participants with dementia, these moments are ineffable and invaluable, even though they are transitory:

‘

The implications for lifelong learning are both philosophical and practical ones. What is it that can be researched in dementia, and how might that be done? In simple terms it seems that dementia may not be a wasteland for learning and that, as this learning seems to add value to difficult lives, it is both hopeful and worth understanding. By focusing closely on Robert, but seeing him as part of an agentic assemblage, we have been able to identify and explore a significant moment of learning in depth. This does not suggest that everyone in late dementia can learn, but it certainly challenges the assumption that they can't. By exploring how Jane experiences time we have shown that people with dementia can teach researchers vital lessons about bodies, materiality, time and meaning. To access such new conceptions and configurations of learning and research, creative engagement combined with a posthuman approach have proven extremely useful. In order to develop this field of research, such transdisciplinary collaborations and methodological innovations will be very important. Posthuman theory is proliferating, but there seem to be few instances where empirical data is used to expand and elucidate that theory. We argue that posthumanism is a vital tool for understanding learning in dementia, but also that people with dementia can add considerably to the development of posthuman understanding and research.

However, we also argue that our paper has implications beyond the field of dementia research and across all the ages of lifelong learning. Posthumanism as a way of thinking and most of all as an approach to empirical research, is very much in its infancy, but it calls into question and overthrows deep-seated assumptions about who the human is and how s/he learns. As Edwards (2016) suggests it marks the end of' lifelong learning as previously configured. However, posthumanism also offers new tools for understanding which need developing and employing for a reconfigured future. As we have shown, posthumanism allows exploration of postverbal learning; when it has gone beyond into another realm where we need to learn how to follow.

Note

1. In the UK, the University of Third Age (U3A) is an organisation supported by the Third Age Trust where members, retired and semi-retired, share their skills and life

experiences: 'learners teach and teachers learn, and there is no distinction between them'. (The Third Age Trust, U3A Website)

Acknowledgements

With special thanks to Anna Batson and Karen Abadie for their insights. Thanks to all our participants and partner organisations and to all at Plymouth Music Zone.

Funding for the Beyond Words project was provided by Arts Council England Research Grants Programme

References

Addams-Price, C. (1998). *Creativity and successful ageing*. New York. Springer.

Barad, K. (2003). Posthumanist Performativity: toward an understanding on how matter comes to matter. *Signs: Journal of Women in Culture & Society*, 28:801-831.

Barad, K. (2007). *Meeting the Universe Half Way: Quantum Physics and the Entanglements of Matter and Meaning*. London: Duke University Press.

Barad, K. (2010). Quantum Entanglements and Hauntological Relations of Inheritance: Dis/continuities, SpaceTime Enfoldings, and Justice-to-Come. *Derrida Today*, 3: 240-268.

Batsch, N.L., & Mittelman, M.S.. (2012). World Alzheimer Report 2012. Overcoming the stigma of dementia. Alzheimer's Disease International. London. Retrieved from <https://www.alz.co.uk/research/WorldAlzheimerReport2012.pdf>

Bennett, C. (2015). *Pond*. London: Fitzcarraldo.

Bennett, J. (2010). *Vibrant Matter*. London. Duke University Press.

Biesta, G. J. J. (2015). *The Beautiful Risk of Education*. London: Routledge.

Bleathman, C., & Morton, I. (1992). Validation therapy: extracts from 20 groups with dementia sufferers. *Journal of Advanced Nursing*, 17, 658-666.

- Bishop, C. (2006). *Participation*. London: Whitechapel & MIT Press.
- Black, D. (2011). What is a face? *Body & Society*, 17: 1-25.
- Bishop, C. (2012). *Artificial Hells: Participatory Art and the Politics of Spectatorship*. London & New York: Verso.
- Boulton-Lewis, G. (2010). Education and Learning for the Elderly: Why, How, What. *Educational Gerontology*, 36, 213-228.
- Braidotti, R. (2013). *The Posthuman*. Cambridge: Polity Press
- Burdick, A. (2016) Present Tense: How to think about time, *The New Yorker*, 19 and 26, 68-74.
- Cheng, S-T., Chow, P.K., Song, Y-Q., Yu, E.C.S., Chan, A.C.M., Lee, T.M.C., & Lam, J.H.M. (2014). Mental and physical activities delay cognitive decline in older persons with dementia. *The American Journal of Geriatric Psychiatry*, 22, 63-74.
- De Certeau, M. (1984) *The Practice of Everyday Life*, London, University of California Press
- Deleuze, G. and Guattari, F. (1987) *A thousand Plateaus*, Minneapolis: University of Minnesota Press
- Edwards, R. (2016) The end of lifelong learning?: A post-human condition, *Studies in the Education of Adults*, Pages 5-17 | Published online: 21 Jan
- Freire, P. (1972). *Pedagogy of the Oppressed*. London: Penguin Books.
- Flood, M., & Phillips, K. (2007). Creativity in older adults: a plethora of possibilities. *Issues in Mental Health Nursing*, 28, 389-411.
- Gale, K. (2016). Theorizing as Practice: Engaging the posthuman as method of inquiry and pedagogic practice within contemporary higher education. In C.A. Taylor, & C. Hughes (Eds.), *Posthuman research practices in education*. London: Palgrave Macmillan.

Gale, K. (2014). Moods, tones, flavors: living with intensities as inquiry. *Qualitative Inquiry*, 20,998-1004.

Guattari, F. (1984) *Molecular Revolution: Psychiatry and Politics*, New York: Penguin

Harries, B. (2013) The Storybox Project: Examining the role of a theatre and arts-based intervention for people with dementia, University of Manchester

Heath, S., Fuller, A., & Paton, K. (2008). Network-based ambivalence and educational decision-making: a case study of 'non-participation' in higher education. *Research Papers in Education*, 23, 219-229.

hooks, b. (1994). *Teaching to Transgress*. London: Routledge.

Ivinson, G and Renold, E. (2016) Girls, Camera(Intra)Action: Mapping Posthuman Possibilities in a Diffractive Analysis of Camera-Girl Assemblages in Research on Gender, Corporeality and Place, In C. A. Taylor and C. Hughes (Eds) 168-186

Jenkins, N. (2014). Dementia and the inter-embodied self. *Social theory & Health*, 12,125-137.

Jones, A. and Hoskins, T. K. (2016) A Mark on Paper: the Matter of Indigenous-Settler History in Taylor, C. and Hughes, C. *Posthuman Research Practices in Education*, Basingstoke: Palgrave MacMillan

Kester, G, (2004). *Conversation Pieces, Community and Communication in Modern Art*, University of California Press, Los Angeles.

Kontos, P.C. (2004). Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing & Society*, 24, 829-849.

Lee, J-Y., & McFerran, K. (2012). The improvement of non-verbal communication skills of five females with profound and multiple disabilities using song-choices in music

therapy. *Voices: A World Forum for Music Therapy*, 12. Available at <https://voices.no/index.php/voices/article/view/644/559>.

Lewis, M. G. (1993) *Without a Word: teaching beyond women's silence*, London: Routledge

MacLure, M. (2009). Broken voices, dirty words: On the productive insufficiency of voice. In A. Y. Jackson & L. A. Mazzei (Eds.), *Voice in qualitative inquiry: Challenging conventional, interpretive, and critical conceptions in qualitative research*. London: Routledge.

Mazzei, L. M. (2016) .Voice Without a Subject. *Cultural Studies-Cultural Methodologies*, 16, 151-161.

Mazzei, L. M. (2007). *Inhabited Silence in Qualitative Research*. New York, NY: Peter Laing.

Mountain, G.A., & Craig, C.L. (2012). What should be in a self-management programme for people with early dementia? *Ageing & Mental Health*, 16, 576-583.

Quinn, J. (2016) Poetry and Posthumanism, paper presented at the International Congress of Qualitative Inquiry, University of Illinois at Champaign-Urbana, May

Quinn, J. Blandon, C. and Batson A. (2017) Beyond Words project: Final Report, Plymouth: Plymouth University, on behalf of Arts Council England

Quinn, J., & Blandon, C. (2014A). The power of songs: An evaluation of Plymouth Music Zone's 'Keep Singing, Keepsake' Project. Available at: <http://www.plymouthmusiczone.org.uk/userfiles/PMZ-'KEEP%20SINGING%20KEEPSAKE'%20EVALUATION%20REPORT-MARCH%202014.pdf>

Quinn, J., & Blandon, C. (2014B). Feeling their way: women and children using music to navigate transitions from domestic violence. Available at:
<http://www.plymouthmusiczone.org.uk/userfiles/MFC%20Evaluation%20Report-Final%20Oct%2014.pdf>

Rancière, J. (2010). *Dissensus: on politics and aesthetics*. New York-London: Continuum International Publishing Group.

Sabeti, S. (2015). Creative ageing? Selfhood, temporality and the older adult learner. *International Journal of Lifelong Education*, 34, 211-229.

Sakamoto, M., Ando, H., & Tsutou, A. (2013). Comparing the effects of different individualised music interventions for elderly individuals with severe dementia. *International Psychogeriatrics*, 25, 775-784.

Sherratt, K., Thornton, A., & Hatton, C. (2004). Music interventions for people with dementia: a review of the literature. *Aging & Mental Health*, 8:3-12.

Silverman, M. (2008). Nonverbal Communication, Music Therapy, and Autism: A Review of the Literature and Case Example. *Journal of creativity in Mental Health*, 3, 3-19.

Sorensen, S. (2012). Dementia and life long learning. Retrieved from
<http://www.learningandwork.org.uk/lifelonglearninginquiry/docs/susanne-sorensen-wellbeing-evidence.pdf?redirectedfrom=niace>.

Commented [CB1]: I cannot find in the document the year of publication.

Taylor, C.A., & Hughes, C. (Eds.). (2016). *Posthuman research practices in education*. London: Palgrave Macmillan.

Tett, L. (2006). Community Education: participation, risk and desire. In Leathwood, C., & B. Francis(Eds.), *Gender and Lifelong Learning: Critical Feminist Engagements*. London: Routledge

Vorhaus, J.S. (2015). Capabilities, human value and profound disability: capability theory and its application to theatre, music and the use of humour, *Disability & Society*, 30:173-184.

Wolf, M.A. (2009). Older Adulthood. In P. Jarvis (Ed.), *The Routledge International Handbook of Lifelong Learning*. London: Routledge.

Woods, B., Spector, A., Jones, C., Orrell, M., & Davies, S. (2005). Reminiscence therapy for dementia (Review). Chochrane Database of Systematic Reviews. Available at <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD001120.pub2/pdf/>.

World Health Organisation (WHO). (2002). *Active Ageing: A policy framework* (WHO/NMH/NPH/02.8). Retrieved from http://apps.who.int/iris/bitstream/10665/67215/1/WHO_NMH_NPH_02.8.pdf.